

Testimony presented to the Senate Health, Human Services and Senior Citizens Committee

March 6, 2008

Good Afternoon Senator Vitale and members of the Senate Health, Human Services & Senior Citizens Committee. I would like to thank you for this opportunity to testify regarding the Division of Developmental Disabilities' Community Services Waiting List (CSWL). My name is Ken Ritchey and I am the Assistant Commissioner for the Department of Human Services, Division of Developmental Disabilities (DDD). Yesterday, I reached my one year anniversary here with the Department and am venturing into my second state budget process.

Please allow me a few minutes to offer some informational and statistical background on the Community Services Waiting List. The CSWL was established in 1985 as a mechanism to provide residential services to individuals with developmental disabilities at a time when requests for services outpaced available resources. The procedure for the waiting list is defined in our Division Circular #8 found on our website. It describes the maintenance of a chronological list of individuals with developmental disabilities waiting for residential services.

There are three sections to waiting list which are defined as follows:

1. The *Priority Waiting* List is assigned when an individual is in need of placement because he or she is determined to be at significant risk or the persons parents are 55 years or older. Other criteria for assignment to the priority category are:

- The individual's health and welfare is determined to be at significant risk;
- Parents can no longer care for the individual, or;
- If a parent or guardian is under 55, there are clear life-safety issues pertaining to the individual's care.

As of January 31, 2008, **4,843** people were on the Priority Category of the Community Services Waiting List (CSWL).

- **3,924** of these individuals were on the Priority Category of the CSWL living at home.
- The remaining **919** are on the list but are living in programs out of the home and are requesting to move or a placement is currently under development.

Many individuals are added to the priority waiting list due to the age of their parent(s). The average age of these parents is approximately 62.

2. The *Priority Deferred* category is assigned when an individual who has turned down an offer of placement, but has asked to remain on the list.

- As of January 31, 2008, **359** people were on the Priority Deferred CSWL.

3. The *General* Waiting List is for individuals who have expressed an interest in residential services but do not meet the priority definition and who may need residential supports in the future.

- As of January 31, 2008, **2,810** people were on the General CSWL.

A Plan to Eliminate the Waiting List for Community Residential Services by 2008 was submitted to the Legislature in January 1998. The Waiting List Plan was funded from 1998 through 2002. The last time there was a large funded initiative to remove people from the CSWL was FY2002. Funding received between FY2003 and FY2007 was primarily to complete the previous initiatives that were designed to be funded over a multi-year period.

Twenty-five percent (25%) of families want to delay a residential placement when it is offered to them, despite the fact that they meet the criteria for the priority waiting list. Many families would prefer to have in-home services and supports for their family member, with an assurance that a residential option would be available if they can no longer provide the care, or the individual's needs change significantly.

We want to be proactive with regard to addressing the multitude of concerns and issues there are with the CSWL. With that in mind, we would like to share with you the steps we have taken to begin to address these issues. The linchpin to offering appropriate supports and services to consumers is funding.

In order to increase funding for services we have proposed an amendment to New Jersey's Community Care Waiver. After review from key stakeholders, including self advocates and family members, we submitted it to the federal Centers for Medicaid and Medicare Services (CMS) for their approval. This amendment, if approved, will include services not currently found under the waiver and allow for the state to bill CMS for an approximate 50% reimbursement. This funding, if reinvested into the DDD system, would address the support needs of families on the CSWL. These are dollars New Jersey is already spending and seeking federal reimbursement.

We also have been looking at how the current CSWL can be revised to be the most beneficial to families. The greater impact on families will be to have a waiting list that is geared towards offering self directed services and supports in the community as opposed to limiting its use to a residential list. We want to support any family which is able to keep their loved one at home and just needs assistance in order to do so.

We understand the interest in the community around this subject is great and we applaud those who have submitted proposals to address the concerns of families with regard to the CSWL. For instance, the Arc of New Jersey has proposed a 10% Solution to provide capital funding and service funding to 10% of the people on the Priority CSWL each year for the next 10 years as a planned effort to create movement on the list. This, like all of our efforts to support individuals with developmental disabilities, will take a concerted effort from many different parties including our Legislators, providers, stakeholders, and families. We believe it is possible to make these changes and expand services for individuals in need throughout our great State of New Jersey. Increasing federal reimbursement is one way to do that. The dollars received back on improved waiver claiming must be reinvested in the DDD system in order to increase services and infrastructure in community programs to address the needs of those on the waiting list.